will occur elsewhere in a pedigree, given that at least one member of the pedigree, the proband, exhibits the disease.

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Denying the Inevitable— The Misplaced Use of Technology

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VAN WAS AN 88-year-old retired engineer who had been failing for months and, to some extent, for years. He was becoming progressively demented from multiple cerebral infarctions. Unfortunately, there was no treatable or reversible cause of his deterioration. He was widowed and had no children, so a niece was responsible for decisions and arrangements for his personal needs and medical care.

His internist, who had been Van's primary physician for many years, had a conference with the niece. Van's prognosis was discussed. The presence of significant multi-system disease and progressive neurologic decline meant that further decline and death were highly likely. The niece, however, was dissatisfied with this outlook. The internist was dismissed, and Van's care was transferred to a tertiary medical center. This center was a teaching institution of premier caliber with a full range of staff and equipment: subspecialists in nearly every conceivable discipline with access to a dazzling array of technological devices. An institution's preeminence in specialty expertise also can be its peril: a frail elderly patient risks becoming dehumanized, a set of diseases instead of a person. Controlling symptoms and providing palliation and comfort do not belong to any one specialty. (This reference to tertiary care centers is generic and is in no way intended to be disrespectful of the fine center where Van spent much of his last year. Nor is excessive medical meddling seen only in tertiary centers. Some physicians treat as long as there is a heartbeat, regardless of a patient's overall prognosis and quality of life.)

When first seen at the medical center, Van could no longer take care of himself, required aid in dressing and bathing, was falling repeatedly, asked the same questions again and again, was disoriented, frequently incontinent, and had lost 30 pounds. He did not know the date, the day of the week, or the name of the President. There is no evidence at any time during his last year of treatment at the center that he improved in any of these abilities. Instead, much of the time he was worse despite—or because of—all the invasions of medical technology.

During his last year he had three computed tomographic studies of his head, an electroencephalogram, a bone scan, a spinal tap, four chest x-ray films, two abdominal x-ray films, a renal ultrasound, an intravenous pyelogram, a retrograde pyelogram, many blood drawings with counts and chemistries, numerous urinalyses, blood and urine cultures, hair tested for arsenic, serum toxicology and heavy metal screens, urine toxicology.

He was in the hospital three times, for a total of 38 days. He was seen in consultation by neurologists, gastroenterologists, anesthesiologists, and urologists. He had a prostate resection. He was examined by many residents, along with countless assessments by dieticians, physical therapists, speech therapists, occupational therapists, and nurse specialists.

He had nasogastric tube feeding and indwelling catheters for months. Various forms of restraints were applied, including Posey, chest, and wrist restraints, body restraints, and hand and foot restraints. Why? Because he pulled out his IV lines and nasogastric tubes. He was given many parenteral solutions, three units of packed red cells, and one unit of whole blood.

At one point, a percutaneous gastrostomy was ordered, but his niece would not give her permission. She was becoming disenchanted with the lack of apparent benefits and the distressing nature of the treatments Van was receiving. She wanted his nasogastric tube removed and her uncle released from the hospital. Under pressure from the attending physician and an Ethics Committee representative, the niece relented. Later an order was written, "Please consult Dr B and Dr W (neurologist and physiatrist): Has this patient an incurable or irreversible condition? Please advise on continuation of nutritional support with respect to ultimate prognosis." Six months before this, the neurologist had written, "I believe his current situation offers no reasonable prospect of recovery."

After a 17-day hospital stay, Van was discharged with a nasogastric tube. Later he could be fed by mouth, but 24-hour nursing care was required. Shortly after his 89th birthday he was reported to be "remarkably better." In fact, he was so much better he was able to die a few weeks later. After nearly a year of modern medical care. Finally!

There are lessons to be learned from Van's terminal year. While modern medical centers can offer dramatic and amazing cures, these are less forthcoming to the chronically ill, debilitated, and demented. The interests of frail elderly persons are often better served by a humanitarian approach that recognizes the limitations of technology.

The niece's expectation of dramatic success led her to seek care at the tertiary center. But with that change there was a loss of perspective that can only be developed in a close personal relationship of many years. Thus, Van entered a system that knew little of who he was—a proud, independent, retired engineer.

To the system he was alternatively a diagnostic or therapeutic challenge, or a placement problem. Diagnostic testing searched for the crucial lesion (such as obstructing hydrocephalus, or arsenic poisoning) which would lead to a dramatic cure. The structure of the academic setting often obscured primary responsibility to the patient by involving multiple layers of housestaff and attending staff. *Continuity*

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was thwarted by rotation of responsibility at the different levels. This diffusion of responsibility was accentuated by the many specialists and allied health professionals who focused on only one organ or system. No one oversaw the thread of illness or appreciated its tragic proportions between the multiple hospital stays.

The atmosphere was generally aggressive in terms of diagnosis and treatment. The values and wishes of this confused elderly patient were ignored. He had no formal advance directive, and therefore nothing impeded the intensity of his treatment. The attitude, often implied if not stated, seemed to be, "We are experts in diagnosis and treatment, and that we will do." This attitude lacked a tempering influence by a physician skilled in the art of the possible.

The dollar costs of Van's terminal year were huge, many times the costs of his medical services for the rest of his 87 years. The real tragedy, however, was not the wastefulness but the indignity suffered by the patient. His dignity suffered as he became an object of technologic interventions. His physicians could not allow him to die. Nor could the Ethics Committee, which found him "neither comatose nor terminal," and therefore forbade removal of his feeding tube.

The primary care internist had seen this tragedy played out before and had foreseen the inevitable end. After Van's death the internist reviewed the medical record because of a legal challenge to the will. He said, "God, don't let them do that to me."

The Examination Room

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FRIDAY AFTERNOON I accompanied my husband, Jim, as he kept an appointment with his internist, Mike Levin. My plans for that afternoon had not included a trip to the medical office building at Newton-Wellesley Hospital, but because Jim had been limping around on a sore foot (a month ago something in his arch went "ping" as he made a heroic effort to save a point on the tennis courts), we both anticipated he might come home in a cast. Reluctantly I rode with Jim to the clinic, consoling myself that I would catch up on *People* or *Newsweek* in the waiting room.

But Jim wanted me to continue to stay by his side, so when Mike's receptionist ushered Jim into an examination room I followed. I didn't even have time to snatch a magazine from the table in the waiting room.

Once inside the small office, which was lit by glaring fluorescent lights, I peered wearily at two plastic models on display. One was a large replica of a human spine, its curve graceful, serpentine. The other was a squat plastic heart that, balanced as it was on a black metal rod, appeared to be skewered like some hunk of meat set aside for a barbeque. The colors of both models seemed garish to me, but since I have never seen the "real" thing I am guessing. White plastic nerves jutting out of the spine were unpleasantly reptilian, like the snakes on Medusa's head. I fidgeted on a black vinyl chair as Jim, from his perch on the examination table, swung his legs, the paper beneath him rustling with every slow arc of leg.

"Don't be alarmed," Jim said to me as he watched his swinging feet, "if my legs don't respond when Mike hits me with his rubber hammer. They never do."

"Never?"

"Never."

I turned my attention to something less grim: a large plastic container that sat on the table to my left. It looked like a fat, jovial cookie jar filled with what, through the opaque plastic, vaguely appeared to be golf tees, little round shapes in white, red, black, and yellow. Curious, I looked more carefully at what was inside the sealed jar. It was filled with used plastic syringes, each one carefully labeled with strips of typed numbers taped around the brightly colored shafts. A ghastly collection, the sinister gray needles evoked sickness and hospitals, dope and death, and, finally, long stretches of beaches littered with the refuse of used medical supplies.

I turned from this menacing jar to the walls of the office. There is usually a magazine stuffed in the hanging rack, but on this day it was empty. A collage on the wall across from me caught my attention. Two photographs were matted and framed with a page of print done by a child and entitled "Forsythia." I looked closer at the photographs. In one a little boy who bore some resemblance to Mike stood proudly at the controls of a power boat; in the other, his back to the camera, he dangled a fishing line into the water below. Next to these images were a few short lines presumably written by the same little boy. The letters, which sprawled upward to the right corner, were of varying sizes, and the "g" and "j" and "d" were all printed backward. This collage, which had been professionally matted and framed, gave evidence of a preserving spirit and parental pride. Assuming that some teacher one fine spring day had assigned her 2nd or 3rd grade class to write a poem about forsythia, I was not too eager to read the poem. I expected lots of references to the color yellow and bright spring days; I did not expect to find anything of much literary value from an eight-year-old. I read the poem.

Forsythia
in the night,
if you are asleep
And only if
you are asleep,
The stars jump
on the forsythia.

BY BEN LEVIN, 1989

I was astonished. I reread the poem, and this time I noticed that the letter "j" was turned around so "jump" appeared to be "lump." The handwriting error made me smile. I read the poem again, and by this time I noticed that Jim had read it too. We sat beaming at each other. Ben's six scrawled lines were marvelously unpredictable and captured a sense of wonder that good poems always do.

William Wordsworth once wrote he was "surprised by joy." I think I shall never forget the shot of joy Jim and I shared on a rainy, cold day in October as we, fearing bad news, sat amid the menacing accoutrements of our internist's examination room and learned from Ben's poem that sometimes at night the stars jump on the forsythia.

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